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ABSTRACT

Discussed are current practices and promising approaches in the development of community-based living arrangements for children and adults with psychiatric or developmental disabilities. Problems with current systems include a lack of safe, affordable housing; lack of consumer choice; inflexibility; lack of a coherent, clear ideology; failure to address deep human needs; and the concept of a continuum of services. Promising approaches that have been identified in the area of residential services for individuals with developmental disabilities include family support services, permanency planning, and individualized living alternatives for adults. Promising approaches in the mental health field also focus on family supports and permanency planning, in addition to emphasizing an individualized, psychiatric rehabilitation approach to housing. Legislative and regulatory barriers to implementation of individualized approaches involve funding mechanisms which are tied to facility types or to the individual's level of functioning based on assessment. (JDD)

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Center on Human Policy

MY HOME, NOT THEIRS:

PROMISING APPROACHES IN

MENTAL HEALTH AND

DEVELOPMENTAL DISABILITIES

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MY HOME, NOT THEIRS: PROMISING APPROACHES IN MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

by Bonnie Shoultz

Though there has been relatively little interchange of ideas between the fields of mental health and developmental disabilities, we are beginning to realize we have much in common. We are coming to know that the needs of the people receiving services in either system are best met through individualized approaches based on values. Categorical labelling, and the resulting development of very different approaches in the two fields, has obscured our ability to see and talk to each other.

This chapter will discuss current practices and promising approaches in the development of community-based living arrangements in mental health and developmental disabilities, and will look at issues having to do with homes for children, adolescents, and adults. The basic position taken is that everyone needs a home, not just housing, that homes should "belong" to the people living in them, and that individualized supports and services should be provided to people in their homes.

The Current Situation in Housing

While complete data on the current living situations of people with severe and/or persistent psychiatric disabilities are not available at national or local levels, it is clear that these situations are vastly different than thirty years ago, when the "deinstitutionalization" movement began.

Communities today try to deal with growing numbers of homeless people, many of whom are thought to have mental illnesses. It is estimated that from 30% to 50% of the adults with psychiatric disabilities are living with family members, often without much support for the family or for the individual (Goldman, 1982; Hatfield, 1984). Large numbers have been discharged from hospitals into nursing homes, which generally provide custodial care and shelter but few if any rehabilitative services. Many others live in other types of custodial situations, such as large board and care homes, adult foster homes, single room occupancy hotels, and shabby apartments, often in situations that place their safety and physical and mental health in jeopardy. People placed in situations such as those described above are very likely to cycle frequently in and out of the hospital, and to continue to require rather large expenditures of public dollars.

Many states, prodded or empowered by the NIMH Community Support Program initiative (Turner & Tenhoor, 1978), have developed other types of community based, rehabilitative residential alternatives for people with severe and persistent psychiatric disorders. States now provide funds (over 300 million dollars in the 1985-86 fiscal year) for supported or supervised apartment programs and group homes, as well as for crisis intervention homes and other nontraditional types of residential services (Ridgway, P., 1986). It is generally recognized that services such as these come much closer to meeting the needs of people with psychiatric disorders than the custodial situations previously described. It is also true,

however, that significant problems exist with these programs, and that people with more severe impairments are not generally to be found in these settings.

In developmental disabilities, most states still have large institutions where it is assumed that people will live out their lives. While some states have made a major commitment to the development of community alternatives and now spend more than half their developmental disabilities budgets in the community (Braddock, 1986), many others are moving very slowly. Few of the homeless are likely to be developmentally disabled, but people with developmental disabilities are commonly found in the other living situations described above--nursing homes, unsupported family and foster homes and apartments, and boarding homes.

The states tend, however, to spend significantly more money on community based alternatives such as group homes and apartment programs for people with developmental disabilities than for people with psychiatric disorders. Many states have invested quite heavily in these types of programs, often using federal funding through the Medicaid program to pay a large amount of the expense. Medicaid has not been available to states for mental health residential services; its availability for people with developmental disabilities has made a tremendous difference in the number and types of community based services provided. Medicaid regulations, especially in states like New York which do not have a Medicaid waiver, are seen by many as restrictive and overly medical; but some states are able to provide individualized, integrated residential supports using the waiver

(Braddock, 1986; Smith & Aderman, 1987). As with mental health programs, significant problems exist with residential services now commonly offered to people with developmental disabilities.

Problems with Current Systems

Lack of safe, affordable housing

A problem in many communities is that rents and mortgages are generally out of the price range of people whose main source of income is government benefits such as SSI or SSDI. The housing people can afford is likely to be located in poor and dangerous sections of the community; Section 8 certificates might help in renting better housing, but there is usually a long waiting list for these. States have responded by providing funds to agencies that operate group living facilities, most of which are constructed or purchased by the agencies operating them. This is a slow and costly solution to this problem.

One expert in housing for people with disabilities (Bob Laux, 1987, conference presentation) recommends that states think about subsidizing rents directly rather than investing heavily in facilities or encouraging agencies to develop facilities. In fact, rent subsidies are available for mental health consumers in 19 states, according to a 1986 survey conducted by Ridgway. A state could even set up loan programs whereby people could be assisted in owning their own homes. Either of these approaches would be much less costly than the facility-based approaches used today. At any rate, it is time that new avenues to resolve this basic problem be developed.

Lack of consumer choice

We are finally beginning to recognize that people with developmental and psychiatric disabilities should be afforded the opportunities the rest of us take for granted: choices over where and with whom we will live. This recognition has cast a new light on the traditional agency-operated programs that have developed over the past 15-20 years. When choices over fundamental matters and minor issues are denied, passiveness and dependency often result. Denial of choice can also lead to struggles for power whereby the service recipient is labelled "manipulative" or even terminated from programs. Either way, the consumer loses.

Inflexibility

Many of today's residential services have rules and regulations set up for group and agency convenience which don't "fit" potential or actual residents of the program, especially those with more severe disabilities. This is especially true in large group settings, but it can also be seen in apartment-based programs. Organizational concerns take precedence over individual concerns, and individuals whose needs cannot be met within the structure must leave. Frequently, rigidity emanates from state or federal regulations. Programs often state that they are required to implement rules with which they don't agree. Inflexibility is a problem in mental health and developmental disability services alike.

Lack of a coherent, clear ideology

The best services we have seen have simple but clear philosophy statements, such as "The purpose of Options in Community Living is to support each person in finding and keeping a space within which to be or become herself." There is a vast difference between this statement and a more typical one, such as "The purpose of the Office of Retardation is to provide residential services in normalized environments to individuals with developmental disabilities," or "The purpose of County Mental Health Services is to reduce the incidence of hospitalization of our residents while maintaining them in the community." Which of us would choose a goal of receiving services in a normalized environment? Are our hopes so low that "reduced incidence of hospitalization" is seen as a purpose? There is a strong need for both mental health and developmental disability services to rethink our values, to move toward the ordinary values of the culture within which we exist, and to use language that reflects that rethinking.

Failure to address deep human needs

Service systems often overlook what are seen in our culture as basic human needs of people, such as the need or desire to have one's own space, to live there as long as one chooses, to express one's individuality, to connect in a meaningful way with other people (especially with ordinary community people who willingly and freely spend time with one). Too often, service systems set up attitudinal barriers, such as the idea that a person doesn't have the skills to take care of a home or to make

a friend, that lead to practical obstacles to meeting these needs. At bottom is the view that service recipients are different than other people, that their disabilities define them and confine them. With that view, bizarre service practices appear to make perfect sense. The result of this "blame the victim" mentality is failure to support people in attaining conditions (such as privacy or choices about one's own routines) and relationships that are taken for granted by everyone else.

The concept of a continuum of services

In an effort to make sense of the variety of residential alternatives available and planned, virtually every state has at some time conceptualized the options it offers in terms of a "continuum of services." The continuum concept, as we will see, has serious negative implications for people with the most severe disabilities or impairments, and is not very positive for others, either. The continuum orders services along a line from most to least restrictive, based on an assumption that people with the most severe disabilities "need" to live in restrictive settings, and that people with less severe disabilities can be arranged (usually based on an assessment of their skills and deficits) according to the level of restriction they "require." Rehabilitative services are often designed for the purpose of moving people to less restrictive settings.

*The ideas presented in this section have been discussed in depth by Taylor, et. al. (1985).

A typical developmental disabilities residential continuum might look like this:

State Institution	Nursing Home	Group Home	Supported Apartment
Private Institution	Community ICF/MR	Foster Care	

A typical mental health continuum might appear as follows:

State Hospital	Boarding House	Transitional Group home	Supported Apartment
Nursing Home	Foster Care	Supervised Apartment	

The problems with the continuum concept are many. First, it assumes that the most restrictive settings are appropriate for people with the most severe disabilities or impairments, that because they need an intensive level of services, they must reside in a segregated setting to receive those services. In fact, innovators in mental health and developmental disabilities have demonstrated that just about anyone's needs (psychiatric, medical, behavioral, therapeutic) can be met in the community; services and supports can be brought to or organized for individuals in their homes rather than in specialized settings. Yet our systems continue to tie services to restrictive settings and to assume that these settings are necessary because the services are necessary.

Second, the continuum concept assumes that people will move as they develop skills or overcome their impairments; this reliance on transition creates a situation where those who are

most vulnerable must undergo major disruptions every time they begin to do well; in effect, they are punished for learning or improving. In mental health services, the problem is often compounded by a requirement that there be a time limit (such as six months) on the person's stay in a setting. Transition, as any of us who have moved frequently are aware, mitigates against development of a sense of home. And yet people with psychiatric or developmental disabilities are expected to spend years of their lives, perhaps most of their lives, in transition.

Third, more restrictive settings are not places where people can learn the skills they will need to live in less restrictive settings. One best learns the skills needed to live in an apartment by being supported in living in the apartment, not by living in a larger group. It is well known that people with severe disabilities have difficulty generalizing skills from one setting to another, but there is a failure to see that this is the expectation behind the concept of movement along a continuum.

Fourth, the continuum doesn't really work the way it is supposed to. Movement from one part of the continuum to another is influenced by organizational concerns, such as availability of space, entry and exit criteria, etc., rather than by individuals' skill development. People who are seen as ready to move must frequently wait months or years to experience the level of independence and self-determination they are "ready" for. The continuum always has bottlenecks.

Fifth, the continuum emphasizes facilities, not individuals. The models for each step in the continuum are facility types. Some say that our field has an "edifice complex"

whereby human needs are subordinated to real estate concerns, to economic interests, and to facility-based concepts of service. Haven't we all heard that this or that person "is appropriate for" a group home but not an apartment? None of the rest of us have to live in facilities--we have homes.

Model Programs, or Promising Approaches?

The Center on Human Policy at Syracuse University operates two federally funded projects, the Research and Training Center on Community Integration and the Community Integration Project. One purpose of both projects is to study "model programs" which integrate people with developmental disabilities into the community and to disseminate the findings of those studies. One of the first things the projects learned was that there is a real problem with the concept of "model programs." The best programs are struggling with their values and their practices, and are eager to discuss their struggles with visitors. Considering a program a "model" almost implies that the program will never change (yet all do, some for the better and some for the worse). It also implies that its procedures can be transplanted and replicated elsewhere, in their entirety, with success.

We at the Center on Human Policy have learned that many of the things we count as mistakes today were seen as models yesterday. We prefer to say that while we have much to learn from good programs, even the best programs should not be spoken of as models. Instead, we prefer to concentrate on "promising practices" or "promising approaches," to isolate what is promising in an agency's approach and to present that without

implying that everything the agency does must be included. One reason we prefer this is that the "model" concept emphasizes the program or agency, while the "approach" concept keeps the focus closer to the individual being served.

Promising Approaches in Developmental Disabilities

Innovators in the developmental disabilities field have been reconceptualizing community living during the 1980s. In 1973 and 1974, Ed Skarnulis (then Residential Division Director in Omaha, Nebraska and now head of the Developmental Disabilities Office in Minnesota) proposed that families should be supported, not supplanted, and that residential services could be provided in a wide variety of environments rather than in group residences. Since then, family support services have been developed in over half the states (Bates, 1985), and in at least one state, the concept of permanency planning guides the provision of out-of-home services to children. For adults, there are now agencies which provide residential supports to people with very severe disabilities in individualized ways, using no group residences whatsoever. The next few pages will look at new approaches in residential services for both children and adults with developmental disabilities.

Family Support Services

It makes little sense to think about providing residential services for children with developmental disabilities without first exploring all possible family support options, yet that is what has happened since the first residential school was opened

for children with developmental disabilities. Family support is relatively new, and in many of its forms, is still very incomplete. In some states, small amounts of respite care are all that the "family support program" offers. In contrast, Michigan and Wisconsin offer two different, but very innovative and effective, types of family support.

Michigan provides direct cash subsidies of $225 per month to families of children with severe disabilities. This subsidy is meant to help families defray the extra costs associated with the care of their child, and can be used for anything from equipment and home renovation to sitters. The only eligibility criteria are that the family's income must be lower than $60,000 annually, the child must be under 18 years of age, and the child must have a severe disability such as severe mental impairment, autism, or severe multiple disabilities, as identified by the public schools. In 1985, 2000 Michigan families received cash subsidies (see Taylor, et. al., 1985, for complete description). Respite and other services are also available in some areas in the state.

Wisconsin's Family Support Program is probably the most innovative nonsubsidy program in this country. It provides up to $3000 per year in services to families in about one third of the state's counties. The Family Support Program is provided through counties, which can offer services directly or contract with agencies to provide them. The program can be used to pay for a broad range of services, depending on what families need. The state lists 15 specific categories of services a family may

receive, and makes provisions for payment for other types of services upon approval (see Taylor, et. al., 1985, for a complete description of the program).

Permanency Planning

Permanency planning, a philosophy of out-of-home care for children, was conceptualized in the child welfare field over the past 15-20 years. Central to the concept is the belief that children who cannot remain in the home into which they were born have a right to a permanent home and to planning efforts to make permanency a reality. Public Law 96-272, the Adoption Assistance and Child Welfare Act of 1980, mandates permanency planning for children served by state social services agencies.

Because children with developmental disabilities have traditionally been the responsibility of state developmental disabilities agencies, permanency planning has not been mandated for them, and the philosophy has not, until recently, been seriously considered. There were at least two reasons for this: professionals believed that children with developmental disabilities required specialized services in specialized settings, and that they could not be placed in foster or adoptive homes because families would not want them. Most states' services for children with developmental disabilities have instead relied on institutional, group home and temporary foster care.

At bottom, permanency planning is no more than a policy affirmation of the basic fact that children develop best in a secure nurturing environment--what we usually call a family home.

The fact that the birth home, for any number of reasons, is not able to provide a child with this nurturing climate does not alter this fact nor obviate a child's right to a home, positive enduring relationships with adults, and an individual advocate who is solely committed to his or her best interests.

The state of Michigan has been in the forefront of states that have used the permanency planning process for children with developmental disabilities. In Michigan, permanency planning for children with developmental disabilities expands on the basic concept and recognizes the special demands which a child with a disability can place on a family. The state regulations describe the process as supporting both children and families. The first priority is to provide what is needed to maintain the child with the birth family. If this fails and temporary placement in foster care is made, the service system begins working towards reunifying the family. If reunification is not possible, services focus on facilitating the adoption of the child; in some cases, an "open" adoption is arranged, wherein there is ongoing involvement by the birth family. If these other goals cannot be achieved, a plan is developed for a permanent foster family, with arrangements for on-going involvement with the birth family (if appropriate) and a guardian or advocate to keep an eye on the best interest of the child. Institutionalization is not considered for any child and, in practice, children are no longer placed in any group setting in Michigan.

Permanency planning cannot work without having concrete services and resources to support children being with their birth families. The same services and resources must be available to

foster and adoptive families. The specialized services needed by children with developmental disabilities, including those with complex medical needs, multiple disabilities, and very challenging behaviors or mental health problems, must be provided to the child's home, whether that be a birth, adoptive, or foster home. It is because these services are available to families that Michigan has been able to avoid placement in group settings during the past four years, when the Permanency Planning Project began.

Individualized Living Alternatives for Adults

The Center on Human Policy has studied several agencies which provide individualized living arrangements for adults with developmental disabilities, including severe and multiple disabilities (e.g. psychiatric disorders, severely challenging behaviors, medical problems, or severe physical disabilities, combined with mental retardation). Unlike most current, facility-based approaches, these agencies help an individual find a home and then build in the supports and services needed by the person to live in that home. The assumption is that people need stable, safe and affordable homes in neighborhoods where they choose to live; that they should be involved in choosing where and with whom they will live, and that they should have control over how they live. Control may mean the right to hire, evaluate, supervise, and fire the staff who work with them; it definitely means control over one's lifestyle and having one's own name on the lease. A need for an intensive level of medical, personal

care, psychological, or other services simply means that those services must be arranged so that the person can live in his or her own home.

Options in Community Living in Madison, Wisconsin provides support to 100 people who are assisted according to Options' mission statement: "to support people in making and keeping a space within which to be and become themselves." Options, a private nonprofit agency which contracts with Dane County to provide residential services, has developed an excellent resource manual which describes its values and procedures in depth (Johnson, 1985). The 100 people supported by Options live in apartments and houses scattered throughout Dane County. The agency has moved away from a "clustered apartment" approach whereby people were served in a cluster of apartments located in an apartment complex. Each person rents his or her own home; if two or more people live together, all their names are on the lease.

About 24 people served by Options employ live-in paid roommates or personal care attendants to provide full-time support, using a variety of funding sources ranging from Medicaid to a special state program (Community Options Program or COP) designed to bring people out of the state institution. For these people, Options acts as a broker--Options helps the people they support to recruit, screen, hire, supervise, and, if necessary, fire their attendants. Options also provides support to about 75 people who do not require live-in assistance but who may need intensive services and supports to remain in their homes. To provide this support, Options has three teams of community

support specialists who provide support, case management, training, and other services to people. All team members know each person supported by their team and can give each other support and assistance as well as problem-solving help when a dilemma arises. The teams also support those who employ live-in attendants, providing in-home training and monitoring as well as assisting with the employment process. Team members, more than attendants, teach skills and provide assistance in the community. If a person needs to see a doctor, go to the bank, or attend a class, a community support specialist is there to assist (Taylor, et. al., 1985; Johnson, 1985).

Another agency that provides individualized supports to adults with developmental disabilities is the Residential Support Program of Centennial Developmental Services, Inc., in Weld County, Colorado. Weld County is the county around Greeley, Colorado. The Residential Support Program, like Options in Community Living, has a philosophical underpinning which guides the decisions made about the 67 people it serves in their own homes and in the homes of community members. First is the belief that all people with disabilities belong in the community; this belief has led the agency to welcome people presenting serious challenges into its program. One woman has periodic psychotic episodes requiring intensive staff supports for several weeks at a time; the agency works with a local psychiatrist to keep her at home. Other people have severe and multiple mental and physical disabilities and are supported in living in their own homes rather than in institutions or group homes.

In the past three years, Centennial Developmental Services (CDS) has moved away from group homes and clustered apartments and toward homes that are dispersed throughout the community. People are assisted in finding appropriate housing in the parts of town where they prefer to live (perhaps near a family or friend or near where they go to work), and may live alone or with others. A number of people live in "host homes," that is, in the home of a person or family in the community. Efforts are made to match the living situation to the person--for some people, living in someone else's home is ideal, while for many others, apartment living with roommates or alone is best. If the person changes his or her mind, or if the situation doesn't work out for any reason, changes are made. Some people have moved several times, having tried something out and realized it was not what they wanted. Just like the rest of us, people who are on their own for the first time may need to try out a variety of experiences, and that should be acceptable. This includes people with complex and challenging needs as well as those who just need a few hours per month of staff time.

CDS promotes increased independence and interdependence for the people it supports, and tries to build in natural sources of support for people. Apartment managers, neighbors, families, coworkers, are encouraged to become involved in people's lives and to provide the kinds of support that might be provided by staff in other agencies. For example, an apartment manager can be called on if Pat, a woman who uses an electric wheelchair, has an emergency at night. Before that, staff lived in an apartment across the hall to ensure Pat's safety. Now, Pat has learned to

dial an answering service in an emergency. The answering service will call the manager, who has developed a special interest in Pat and likes to spend time with her (Walker & Salon, 1987).

A number of promising approaches used by both Options and CDS can be listed: homes are in normal settings and are small scale and dispersed throughout the community; individualized supports are provided; learning takes place within normal daily routines; "programs" for learning skills are individually designed; teams of support staff are involved with each person; there is a great deal of support for staff, so that staff feel they are working toward common goals; relationships are fostered between staff and people they support ; individualized funding streams are made available by the state; consumer choices and preferences are followed; people are helped to become connected to the community; families are involved in people's lives. The effect of these practices is that the people with disabilities who are supported in these ways are much more likely to be accepted in their communities and by their families as people with normal social roles and aspirations.

Promising Approaches in Mental Health

Children and Adolescents with Psychiatric Disorders

Children and adolescents with psychiatric disorders, like those with developmental disabilities, need enduring relationships with one or more adults. Yet one of the hallmarks of psychiatric disorder is that relationships are disturbed and very difficult for all parties to the relationship. The professional response to this problem has traditionally been to

offer therapy for the child, the parents, or the family, or to hospitalize the child. Family supports such as in-home assistance for difficult times of the day, respite care, or cash subsidies are virtually nonexistent; where such supports are offered, they are usually provided in the context of a time-limited, intensive family therapy program which is intended to correct or change family dynamics.

NIMH's Children and Adolescent Service System Program (CASSP) initiative is beginning to discuss family supports such as are offered in many states to families of children with other severe disabilities; perhaps the day will come when out-of-home placement of children with severe psychiatric disorders is not considered unless family support services have been offered and have failed to alleviate the need for the child to leave the birth home. The same types of services, incidentally, should be made available to families who have an adult child with a psychiatric disability living with them.

Permanency planning is another concept that should be implemented in children's mental health residential services. To relegate children and adolescents with psychiatric disorders to group care, often in long term hospital settings, is to cut them off from normal childhood experiences, including the experience of having a stable relationship with one or two adults rather than with rotating shifts of adults. Defying the commonly held belief that no one would want children with psychiatric problems, Michigan's Permanency Planning Project has found and supported permanent foster and adoptive homes for children who have psychiatric disorders together with developmental disabilities.

Specialized foster care projects in many states are providing quality, well-supported foster care for children with psychiatric disorders. It is time for permanency to become an issue in the lives of these children and all children in out-of-home care.

Homes for Adults with Psychiatric Disabilities

The Community Residential Rehabilitation Project at Boston University's Center for Psychiatric Rehabilitation has been studying community residential services for adults with psychiatric disabilities since 1985. The project speaks of "a psychiatric rehabilitation approach to housing" (Carling and Ridgway, 1987) and is developing a "supported housing model" to detail the approach (Ridgway, under development). According to Carling and Ridgway (1987), the new approach will move away from facility-based services and toward assisting people to choose, acquire, and maintain stable, decent, affordable housing; it will recognize that people change, often dramatically and rapidly, and will therefore build in the flexibility to lessen and increase the level of support according to need rather than requiring people to move when their needs change; and it will recognize that "home" is a basic support, a place of rest, not a service program. In short, the new approach will emphasize everything that goes into the ideal of "home" for the rest of us: choice, support, "fit" between the person and the living environment, and refuge.

Carling and Ridgway (1987, p. 10.) note that the new approach is individualized and is especially appropriate for those with severe psychiatric disabilities, in "stark contrast to

the prevailing practice in the field to 'congregate' severely disabled persons in group living programs." The mission of psychiatric residential rehabilitation becomes "to assist people with psychiatric disabilities to succeed in housing of their choice with the least amount of help from formal helping systems," (p. 10) and its principles include access and choice, consumer involvement and control, involvement of family members, use of normal environments (i.e., normal community housing rather than purpose-built or -purchased facilities) and roles (e.g., tenant, neighbor, etc.), learning skills in the home in which they will be used, availability and responsiveness of supports, provision of supports for indefinite duration, and advocacy." (pp. 11-15.)

It is evident that what is being proposed here (see Appendix for another formulation) is a radical departure from the traditional approaches to providing community residential services for people with psychiatric disabilities. Although Carling and Ridgway describe no programs which are using this approach, it is possible to identify agencies whose residential philosophy includes some of the principles listed above. New York City's Fountain House, for example, has a strong residential program which promotes choice, available and responsive supports, indefinite duration, learning in one's home, and (with a few exceptions) use of normal environments. Wisconsin's PACT program (Stein and Test, 1978) apparently provides flexible, responsive supports for an indefinite duration, and promotes choice and family involvement.

It is evident, also, that what is being explored in the psychiatric rehabilitation approach is very like what is being explored in innovative developmental disabilities services such as Options and CDS.

Enabling Structures

Legislative and regulatory barriers to implementation of the individualized approaches described above exist in almost every state. In many states, funding streams are tied to facility types or to levels of functioning based on an assessment. In developmental disabilities services, when these assessments exist they have typically developed within a state for the purpose of determining funding. States are recognizing the difficulties with this approach, however, and are implementing new structures to enable individualization and flexibility.

Wisconsin has undertaken to change funding patterns to allow for development of individualized services for people with disabilities of all kinds. Its Community Options Program (COP) provides funds that go directly to consumers to purchase services such as housing and residential support services. COP funds can be used along with other state funds and SSI payments to allow people to move from institutions into community settings, including their own homes or apartments.

Other states which have recently instituted individualized funding in developmental disabilities services include Maryland (Individualized Support Services), Colorado (Personal Care Alternatives), and North Dakota (Individualized Supported Living Arrangements). Each of these states is experimenting with these

new approaches, and each relies on individually-negotiated contracts for every person served under its program. Each of these states had rate structures based on level of client functioning prior to the initiation of the new programs, and has added the individualized rate to the existing rate structure rather than replacing it.

Nebraska, a pioneer in development of individualized community residential services for persons with mental retardation, has never had a rate structure for its mental retardation services. Instead, each of Nebraska's six mental retardation regions receives an allocation of dollars annually from the legislature; decisions about how the money will be spent are made at the regional level. Residential services and supports vary widely from person to person in some Nebraska regional programs, and people with very severe disabilities are supported to live in communities in individualized settings.

Each of the states mentioned has a complex set of laws and regulations that should be studied by advocates for change to an individualized system of supports for people with developmental or psychiatric disabilities. The National Association of State Mental Retardation Program Directors has recently published a manual, Paying for Community Services (1987) which describes every type of funding mechanism used by state developmental disabilities offices, including the individualized programs described above; this manual should be extremely useful to advocates for change in mental health services, as well.

Summary

Serious problems exist with the residential services offered to people with psychiatric disabilities and to people with developmental disabilities. Children and adolescents with these disabilities are not supported to remain in their own homes, and are typically moved into group or institutional care when they are placed out of the home. Adults are typically served within a continuum of services and are expected to move when they gain or lose skills or symptoms. The services that have traditionally been available are alien to concept of "home" as a place of refuge and stability. Advocates for change are looking at programs and states which support people in individualized ways, which help each person to find and maintain a home.

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APPENDIX

MISSION AND OBJECTIVES OF SUPPORTED HOUSING

(by Priscilla Ridgway; transcribed from notes taken from a presentation by Tony Zipple at a conference in Nebraska, September, 1986)

The Mission of Supported Housing

The mission of supported housing is to assist persons with psychiatric disabilities to succeed in the housing of their choice with the least amount of help from formal helping systems.

The Objectives of Supported Housing

* Ensuring access, as soon as possible, to typical integrated community living situations.
* Permanent or very long-term stable housing--a home.
* Concentration on rehabilitation--teaching skills the person needs.
* Provision of a wide variety of supports, of varying intensity, in the living environment for an indefinite period of time.

Key Principles of Supported Housing

* Client choice
* Real choices/real housing
* Flexible/nonlinear individualized process
* Community integration
* Service system responsiveness
* Respect and dignity/hope and humility

Components of Supported Housing

* Housing development
* Matching the person and the living environment, to include:
  * Goal setting
  * Environmental analysis and client assessment
  * Matching the person to a particular living situation
  * Ongoing planning
  * Off-site and on-site skills training and supports
  * Ongoing assessment and feedback
  * Retention and follow-up
  * Evaluation

Features of Supported Housing

* Private sector housing development
* Stable living environments in typical housing
* Explicit client-based goals and plans
* Functional orientation
* Extensive individualized supports provided over an extended period
* Flexibilty and individualization
* Constant feedback and programmatic change